COVER SHEET

Hardy, J and Dingle, K and Beebe, H and Yates, P (2005) Creating a palliative care research network in Queensland, Australia – is this the answer? . *Progress in Palliative Care* 13(5):pp. 277-281.

Creating a Palliative Care Research Network in Queensland Australia – Is this the answer?

Professor J Hardy BSc, FRACP, MD
Director of Palliative Care
Mater Health Services
Brisbane, Australia

Ms K Dingle, RN, Bed, MPH (TH),
Research Officer
Centre for Palliative Care Research and Education
Brisbane, Australia

H Beebe, RN, BN
Research Officer
Centre for Palliative Care Research and Education
Brisbane, Australia

Professor P Yates, FRNA, DipAppSci, MSocSci, PhD
Director of the Centre for Palliative Care Research and Education
Brisbane, Australia

Address for correspondence:
Prof JR Hardy
Dept Palliative Care
Mater Health Services
Raymond Tce,
Sth Brisbane, Qld 4101
Australia

Tel: + 61 (0) 7 3840 2775/8074
Fax: + 61 (0) 7 3840 8856
e-mail : janet.hardy@mater.org.au

Abstract

Research in palliative care is notoriously difficult. The formation of research networks may be one way to facilitate research in this difficult area. In order to map current research activity and to gauge interest in the formation of a research network, a questionnaire was sent to all palliative care providers in Queensland, Australia. The majority of respondents (63%) had had no prior experience in research in palliative care. The most common barriers to research were a lack of time, support, funds, and experienced personnel. Sixty percent of respondents voiced an enthusiasm for starting a network resulting in the formation of the Queensland Palliative Care Research Group. The key objectives of the group are to promote research throughout the state and to provide a forum for collaboration, exchange of ideas and the sharing of research experience.

Introduction

The difficulties inherent in undertaking research in palliative care are well recognised (1). The patients are by definition of poor performance status, with multiple symptoms, and progressive disease often complicated by cognitive impairment. Their condition is not stable but changes continuously. Problems are frequently encountered, not only in patient recruitment but also in patient attrition especially with studies of more than a few weeks duration (2). Difficulty in completing assessments often results in missing data. Many health professionals are concerned by the vulnerability of patients and the unacceptable "burden of participation" associated with trial entry. Palliative care patients are thus shielded or "protected" from entering trials.

Few would argue with the need to evidence base the practice of palliative care however, most health care professionals recognise that such evidence is dependent on high quality research. A number of strategies have been proposed in an attempt to improve the success of research in this area. These include the acceptance of simplified information and consent forms (3), modified consent processes (4) and the development of standardised measurement tools (5). Some have suggested a shift to qualitative research however at present there is no standard means of rating the evidence from qualitative studies (6) and controlled trials remain the gold standard. Further the research workforce in palliative care is often fragmented and in most countries with only a very small proportion of total research monies is directed towards supportive and palliative care research.

It has been suggested that the formation of research networks might provide another means of facilitating research in this difficult area. In order to develop a palliative care research network in Queensland, Australia, we elected to survey all palliative care providers in the State. In doing so, we hoped to ascertain interest in the formation of such a network, to map all current research activity, to identify problems that, have been encountered in undertaking research to date, to create a data base of current research and to solicit ideas as to how a research network might help individual units.

Method

A questionnaire survey was developed in two sections, according to whether or not the respondent had prior experience in research. Those who had undertaken research in palliative care were requested to list the types of research they had undertaken in the past and for a list of current research projects. They were also asked about problems experienced in completing research studies and their experience in applying for research grants. Those who had never

undertaken research were asked if they would be interested in doing so and what, if anything, had prevented them from undertaking research in the past. All respondents were asked if they would be interested in joining a research network.

The questionnaire was sent to all palliative care providers in Queensland as identified from the Palliative Care Queensland National Directory 2004 (7) and to relevant department heads at universities. Key stakeholders at each institution were asked to respond on behalf of all researchers in the unit. A reminder letter was sent to all non-responders after 6 weeks. Telephone follow-up was used to answer queries, resolve ambiguities and to encourage non-responders.

Providers were categorised as hospital based palliative care services, community health services/organisations, hospices, palliative care organisations or universities.

Results

Sixty-three of 85 questionnaires sent were returned (74% response). The response rate according to provider category is shown in table 1. Almost half the responses (46%) were from hospital-based palliative care services. The majority of respondents (40/63, 64%) had had no prior experience in research in palliative care (table 1). The types of research undertaken by the 23 respondents who had undertaken research is shown in table 2.

Of the 23 respondents with experience in palliative care, 12 (52%) had been involved in a study that was never completed. Only 3 (13%) had been involved in a study sponsored by a pharmaceutical company. Sixteen (70%) of this group had applied for a research grant and almost half (48%) had been successful in a grant application.

Of the 40 respondents with no experience in palliative care research, 20 (50%) expressed an interest in doing research, 18 (45%) had no interest and 2 (5%) were unsure. The most common reasons given for not doing research were a lack of time, lack of support, funds, and an absence of personnel and/or expertise (table 3).

Twenty-nine studies were registered by 14 different units (5 universities, 3 hospital based palliative care units, 3 hospices, 2 community based services and 1 palliative care organisation). The majority of studies registered were randomised controlled studies (RCT) (11 RCT, 6 surveys, 6 qualitative interviews, 3 case reviews, 2 audits and 1 laboratory based study).

The majority of respondents (60%), especially those who had undertaken research in the past (96% as compared to 40% of those without research experience) voiced an enthusiasm for starting a research network. Subsequently, the Queensland Palliative Care Research Group (QPCRG) has been formed. The key functions and objectives of the group are to promote palliative care research throughout Queensland and to provide a forum where any health care professional involved in palliative care can collaborate, exchange ideas and share research experience. The group meets 3 monthly and serves to educate members on topics related to research (eg ethics and statistics appropriate to palliative care) and to support those undertaking research. Members are encouraged to present current or planned projects and also to present ideas that might be taken forward at a future date. The group works collaboratively with the Centre for Palliative Care Research and Education (CPCRE), an academic palliative care centre based in Brisbane (8). A primary aim is to develop a trial that can be run across multiple sites and care facilities of sufficient quality to attract funding from a national health research funding body.

Discussion

The results of the current research survey undertaken in Queensland may well be skewed by the relatively large number of university groups that responded. This might also explain the relatively large number of RCT undertaken. Controlled trials are particularly difficult to undertake in palliative care and surveys of published studies in the past have pointed to the lack of RCT and the preponderance of uncontrolled studies (9). It was encouraging to see the number of grant applications that had been submitted and the relatively large number of units that had been successful in obtaining such grants. This may also reflect the number of academic units responding to this survey but also suggests that sources of funding are available in Australia for this type of research. It has been suggested that lobbying to make palliative care research a funding priority might overcome one of the barriers to research in this specialty and that small units should support large academic units rather than undertake research independent of such groups. The small number pharmaceutical led studies would suggest that workers in the field are determining their own research agendas.

Individual units do not always have the necessary resources in time, funding or access to patient numbers and/or research expertise to enable them to conduct high quality research. Research networks have the potential to include health care professionals across a wide number of different sites and disciplines. Health care providers have access to potential trial participants whilst collaboration with academic institutions provides staff and facilities required to analyse and interpret trial data (10). Some of the potential advantages of a network approach are listed in Figure 1. They include the ability to recruit larger numbers of patients, the sharing of new research ideas and the championing of new researchers through an interaction with, or exposure to the expertise and leadership of established investigators. Many research networks are multidisciplinary, whereas others have been created for specific groups of health professionals, for example nurses (11) and dieticians (12).

The National Cancer Research Network (NCRN) in the UK was created in response to the need to improve the infrastructure for clinical research in cancer and to ensure that research is better integrated with cancer management (13). Thirty-four research networks have now been formed with funding for research staff, data managers, medical staff sessions and IT systems. The aim is to improve the speed, quality and integration of research, ultimately resulting in improved patient care. The Palliative Care Development Group is a national body that has been convened through the National Cancer Research Institute (NCRI) to develop and support research in palliative care through these research networks. A collaboration of medical charities has recently agreed to fund research networks in supportive and palliative care. On a smaller scale, local research networks such as the South London Palliative Care Research Group have been developed to encourage and support local units to undertake and complete research.

In the United States, a number of community practice-based research networks have been established with the goal of promoting and conducting practice-based primary care research in the community and to implement findings. The population based Palliative Care Research Network (PoPCRN) is a hospice-based research network modelled after successful primary care research networks. It is based within the University of Colorado Health Sciences Centre and consists of over 120 hospice organisations in 25 U.S. States and Canada (14). Their mission is to enhance the care of persons at the end of life and their families through the conduct and dissemination of high-quality research in palliative–care settings.

In Australia, an example of the network approach is provided by the Palliative Care Clinical Research Group in Victoria. This multidisciplinary group of doctors, nurses, pharmacists and research co-ordinators who are part of the state clinical oncology research group (VCOG), aim to provide a collaborative forum for palliative care research. Palliative Care Australia recognises the need for both national and international collaboration in research activities (15) and this incentive has been supported by the primary national funding body (the National Health and Medical Research Council). Through the National Palliative Care Program, the National Health and Medical Research Council has funded a $4 million collaborative research program in palliative care which has provided support through a number of targeted research grants, short studies, post-graduate scholarships, fellowships and research workshops. A key objective of this research program has been to build research capacity, by fostering collaborations between researchers. Similarly, the National Institute of Clinical Studies (NICS) in Australia is actively supporting the network concept by funding projects that identify gaps between what is known, from the best available research, and what is done in day-to-day practice. NICS will then support health professionals to fill the gaps identified within Australian health care settings (16).

In summary, the network principal seems to be the preferred model of the future for palliative care research. Networks such as PoPCRN (14) have proven track records and documented success as determined by grants won and completed trials published. It remains to be seen whether this can be replicated by a network approach to palliative care research in Queensland.

Figure1. Potential benefits of a research network

- encouragement of new researchers through an interaction with, or exposure to expertise and leadership of established investigators
- foster development of new research methods and designs
- provide training ground for new investigators
- to advance research agendas
- provide a mechanism to meet research needs of individual units
- improve patient care by developing evidence based practice
- encourage dissemination of study results
- encourage uptake of evidence-based practice

Table 1. Response rate according to provider category.

Palliative Care Organisation Type				
	Number of surveys sent	Number of responses (%total sent) total = 63	Proportion of responders %	Number with research experience (valid %)
Hospital Palliative Care Service	34	29 (85)	46	11 (38)
University	18	11 (61)	18	5 (45)
Community Health Service or organisation	26	16(62)	25	3 (19)
Hospice	6	6(100)	9	3 (50)
Palliative Care organisation	1	1 (100)	2	1 (100)

Table 2. Type of research previously undertaken

Type of research	**Total n=23**	Hospital N=11	Uni/PC Organ N=6	Hospice N=3	Community N=3
	Yes	Yes	Yes	Yes	Yes
Survey	**19**	9	5	3	2
Prospective data collection	**10**	4	4	1	1
Observational Study	**3**	0	2	0	1
Needs Assessment	**10**	4	3	2	1
Non-randomised comparative study	**1**	1	0	0	0
Retrospective case review	**10**	7	1	1	1
Qualitative interview study	**11**	4	3	2	2
Systematic interview study	**5**	2	2	1	0
Randomised control study	**13**	6	4	2	1
Audit	**2**	2	0	0	0
Systematic Review	**1**	0	0	0	1

Table 3. Barriers to undertaking research identified by respondents with no palliative care research experience

Number of Responses	**Total n=40**	Hospital n=18	Uni/PC Organisation n=6	Hospice n=3	Community n=13
What has prevented you from doing research in palliative care?					
Lack of Interest	**7**	1	2	0	4
Lack of time	**33**	15	3	3	12
Lack of Support	**22**	9	2	3	8
Lack of Funds	**30**	13	2	3	12
Lack of Personnel	**27**	11	3	3	10
Lack of expertise	**28**	11	4	3	10
Low Priority	**11**	6	2	0	3
Can't see the need	**1**	1	0	0	0

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